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# Contemporaneous and Advance Requests: The Fight for Rights at the End of Life

***R (Burke) v GMC* [2005] 3 FCR 169; *Burke v UK* (application 19087/06)**

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Ken Mason once gave a lecture in which he sought to identify the five most significant UK medical law cases of the past 30 years.<sup>1</sup> His choice predates the *Burke* litigation,<sup>2</sup> but even so I doubt that the decision of the Court of Appeal would now be one of his choices. In fact, Mason's selection includes only one of the 15 landmark cases in this collection.<sup>3</sup> There is simply a huge number of medical law cases illustrating the content of medical law, advancing legal principle and likely to feature in future development of the law. Why, then, does this chapter focus on *Burke*?

There are two particularly striking features of the *Burke* litigation. First, it was the seminal – and currently only – case dealing with a patient's request for artificial nutrition and hydration (ANH)<sup>4</sup> to be continued. Secondly, its true significance results not so much with what it did, but rather what it did not do. The first instance decision of Munby J sought to recognise circumstances in which a patient had a legal right to be provided with life-prolonging treatment, but was overturned by the Court of Appeal, whose judgment later received the support of the European Court of Human Rights (ECtHR). Many commentators have supported the overturning of Munby J – variously declaring that it was 'surely right' that his decision was appealed,<sup>5</sup> the decision was 'unsatisfactory'<sup>6</sup> and the outcome of the appeal was 'probably unsurprising'.<sup>7</sup>

It will be argued in this chapter that the first instance decision was interpreted uncharitably and that the Court of Appeal thereby missed the opportunity to give proper recognition to the rights of potentially vulnerable patients. Further, while the law is still some way from recognising a right to treatment of the form suggested by Munby J, it will be shown that the subsequent case law displays a willingness to grant greater weight to the previously autonomous wishes of an incapacitated patient than the Court of Appeal had been willing to countenance in *Burke*.

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<sup>1</sup> JK Mason, 'Law and Medical Ethics: Have We Learnt Any Lessons?' Unpublished lecture held in Edinburgh Law School on 31 October 1998. For discussion see GT Laurie, 'The Autonomy of Others: Reflections on the Rise and Rise of Patient Choice in Contemporary Medical Law' in SAM Mclean (ed) *First Do No Harm* (Ashgate Publishing 2006), 131.

<sup>2</sup> *R (Burke) v GMC* [2004] EWHC 1879 (hereafter HC); [2005] EWCA 1003 (hereafter CA); *Burke v UK* (No. 19807/06, 7 July 2006).

<sup>3</sup> Mason's selection: *Re B* [1981] 1 WLR 1421, *Gillick v Norfolk and Wisbech AHA* [1986] AC 112, *Re MB* [1997] 2 FCR 541, *A-G's Reference (No. 3 of 1994)* [1998] AC 245 and *R v Cox* (1992) 12 BMLR 38.

<sup>4</sup> The latest GMC guidance refers to 'clinically assisted', rather than 'artificial', nutrition and hydration: see GMC, *Treatment and Care Towards the End of Life* (GMC 2010), para 3. This chapter retains the language used in the *Burke* litigation.

<sup>5</sup> R Gillon, 'Why the GMC is right to Appeal Over Life Prolonging Treatment' (2004) 329 *BMJ* 810, 810.

<sup>6</sup> JK Mason and GT Laurie, 'Personal Autonomy and the Right to Treatment: A Note on *R (on the application of Burke) v General Medical Council*' (2005) 9 *Edin LR* 123, 132.

<sup>7</sup> Emily Jackson, *Medical Law* (Oxford University Press 2013), 968.

A preliminary terminological issue arises with regard to the distinction between possession of sufficient cognitive faculties to be able to make a decision with respect to the given situation and possession of the decision-making authority required for a legally valid decision.<sup>8</sup> A minimum condition of the latter is the ability to communicate, whereas a patient who lacks the ability to communicate may still be considered to have the ‘locked in’ cognitive ability to make a decision.<sup>9</sup> Elsewhere, I have referred to cognitive decision-making ability as *competence* and legal decision-making ability as *capacity*.<sup>10</sup> In the *Burke* litigation, Munby J and the Court of Appeal use these labels exactly the other way around.<sup>11</sup> The terminology used in *Burke* is now potentially confusing when referring to the two-stage test in the Mental Capacity Act 2005, which is a test for legal decision-making authority requiring an ability to communicate and would therefore be described as a competence test in their terminology. In this chapter, I will use my own terminology except when quoting.

## Background

Leslie Burke had a degenerative brain condition that would eventually remove his ability to swallow and require him to receive ANH to survive. The evidence identified three stages that Burke might pass through: the first when he has capacity and is aware, the second when aware of his surroundings and predicament but unable to communicate (ie is ‘locked in’), and the third after lapsing into a coma.<sup>12</sup> Thus, his prognosis was that he would be, in my terminology, (1) capacitated, then (2) competent but incapacitated, and then (3) both incompetent and incapacitated.

Burke was concerned that the guidance of the General Medical Council (GMC)<sup>13</sup> would permit ANH to be withdrawn while he remained aware (ie stages 1 and 2) and he emphatically did not ‘want to die of thirst’.<sup>14</sup> He therefore brought judicial review proceedings against the GMC, claiming that the guidance was incompatible with his rights under the European Convention on Human Rights (the Convention): Art 2 (the right to life), Art 3 (the prohibition of inhuman and degrading treatment) and Art 8 (the right to respect for private and family life). While Munby J was willing to declare that parts of GMC guidance were unlawful,<sup>15</sup> the Court of Appeal took a different view and Burke’s subsequent application to Strasbourg was similarly unanimously dismissed.

Munby J’s 225-paragraph judgment granted six declarations.<sup>16</sup> The first three

<sup>8</sup> An example of this distinction between cognitive and legal decision-making ability is presented where a child with full understanding is denied the legal authority to refuse treatment in the face of parental consent, as per *Re W (A Minor) (Medical Treatment: Court’s Jurisdiction)* [1993] Fam. 64, esp [84] and [86].

<sup>9</sup> Munby J (HC [45]) notes that Lord Mustill in *Airedale NHS Trust v Bland* [1993] AC 789, 897 made reference to a ‘patient suffering the mental torture of Guillain-Barré syndrome, rational but trapped and mute in an unresponsive body’.

<sup>10</sup> See further SD Pattinson, *Medical Law and Ethics* (4th edn, Sweet & Maxwell 2014), ch 5.

<sup>11</sup> See eg ‘a patient who is incompetent, because unable to communicate, may otherwise be functioning with intellect and senses wholly unimpaired’ (HC [45]) and ‘[a] patient is competent if he has the capacity to take logical decisions and the ability to communicate those decisions’ (CA [10]).

<sup>12</sup> HC [170]; CA [36].

<sup>13</sup> See GMC, *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making* (GMC 2002). See the replacement guidance: GMC (n 4) esp 119–122.

<sup>14</sup> HC [6].

<sup>15</sup> GMC (n 13) paras 13, 16, 32, 42 and 81.

<sup>16</sup> HC [225].

declarations specifically concerned Burke and the other three concerned the GMC's guidance. According to the first declaration, any decision by Burke while he has *capacity*, or contained in a valid *advance directive*, requesting that he be provided with ANH is determinate that such provision is in his best interests, at least in circumstances where death is not imminent and he is not comatose. According to the second and third declarations, any such decision by Burke would also mean that a hospital that has assumed his care must arrange for ANH, and a doctor who has assumed his care must either continue to arrange for the provision of ANH or arrange for his transfer to a doctor who will, in the period until Burke's death is imminent and he is comatose. The other three declarations specified paragraphs in the GMC guidance that were unlawful. The guidance was said, in particular, to fail 'to acknowledge the heavy presumption in favour of life-prolonging treatment and that such treatment will be in the best interests of a patient unless the life of the patient, viewed from that patient's perspective, would be intolerable'. Further, there were a number of situations where it would be unlawful to withdraw ANH from an incapacitated patient without judicial sanction.<sup>17</sup>

The Court of Appeal, in overturning Munby J's declarations, ruled that they had extended well beyond the law relating to the patient.<sup>18</sup> Mr Burke was not faced with doctors who wished to withdraw life-prolonging ANH against his will and, in the view of the court, he had not made an advance directive/decision.<sup>19</sup> The court ruled that Burke should have sought reassurance from the GMC, whose guidance was not unlawful. Lord Phillips, giving the judgment of the Court of Appeal, opined that the application had served no useful purpose. According to his Lordship, it had not been open to doubt that the common law (like Art 2 of the Convention) imposes a duty on those who care for a capacitated patient such as Burke to provide ANH as long as it prolongs his life and is in accordance with his expressed wishes.<sup>20</sup> Any doctor who brought an end to a patient's life by withdrawing ANH in such circumstances would be guilty of murder.<sup>21</sup>

The Court of Appeal, after allowing submissions from no fewer than seven interveners, firmly asserted that it was not the role of the court to act as a 'general advice centre'.<sup>22</sup> Steps were taken to limit future judicial involvement to that of adjudicator of last resort. For a start, there remained no legal duty to obtain court approval before treating an incapacitated adult, even if that treatment involves the removal of ANH.<sup>23</sup>

The European Court of Human Rights ruled the application to be 'manifestly ill-founded'.<sup>24</sup> The Strasbourg court took the view that English law adequately protected his rights under Articles 2, 3, 8 and 14. The court considered itself 'satisfied that the presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention'. Further, there was no duty to obtain judicial authorisation for the withdrawal of ANH, as this would be 'prescriptively burdensome', and there was no discrimination in the exercise of his Convention rights contrary to Art 14, as neither a capacitated nor incapacitated patient

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<sup>17</sup> HC [202].

<sup>18</sup> CA [20]. The judgment of the Court of Appeal was given by Lord Phillips.

<sup>19</sup> CA [22].

<sup>20</sup> CA [39]–[40].

<sup>21</sup> CA [34].

<sup>22</sup> CA [20]–[21].

<sup>23</sup> CA [70].

<sup>24</sup> *Burke v UK* (No. 19807/06, 7 July 2006).

‘can require that a doctor gives treatment which that doctor considers is not clinically justified’.

### **Withholding and withdrawing life-prolonging treatment from capacitated patients**

Both Munby J and the Court of Appeal accepted that, while Burke has capacity, those who care for him have a duty to provide him with ANH for as long as it prolongs his life and is in accordance with his expressed wishes. There was, however, some divergence with regard to how they reached this conclusion and its ambit. The essential difference is that Munby J supported his conclusion by reference to Burke’s rights, whereas the Court of Appeal relied entirely on the obligations imposed by the common law on those who accept the care of a patient.

Munby J examined both the common law and the Convention, as given domestic effect by the Human Rights Act 1998, to arrive at a set of legal and ethical principles.<sup>25</sup> His Lordship identified: the *sanctity of life* (protected by Art 2), *dignity* (protected by, in particular, Art 3) and *autonomy or self-determination* (protected by, in particular, Art 8). The right to die with dignity was derived from analysis of the case law, particularly the case law on Art 3, and was said to encompass the right to be protected from treatment and lack of treatment ‘which will result in one dying in avoidably distressing circumstances’.<sup>26</sup> The right to autonomy or self-determination was given even greater emphasis. Various common law authorities – addressing the right of a patient with capacity to refuse treatment, contemporaneously and by advance directive – were cited as indicative of the ‘absolute nature’ of this right.<sup>27</sup> Autonomy was also shown to underpin Art 8, which was said to embrace ‘such matters as how one chooses to pass the closing days and moments of one’s life and how one manages one’s death’.<sup>28</sup>

In contrast, the Court of Appeal ruled that the common law authorities cited by Munby J were concerned solely with the ‘paramount right to refuse treatment’ and ‘the right to self-determination does not entitle the patient to insist on receiving a particular medical treatment’.<sup>29</sup> There was, the Court of Appeal declared, a legal duty to provide ANH to a capacitated patient, because the case law shows that ‘[o]nce a patient is accepted into a hospital, the medical staff come under a positive duty at common law to care for the patient’.<sup>30</sup> This duty will not override the wishes of a capacitated patient who refuses ANH, but where a patient wishes to be kept alive by ANH ‘this will not be the source of the duty to provide it’.<sup>31</sup>

There was thus a key difference between the approach at first instance and the approach on appeal: Munby J had concluded that while Burke had capacity he had the *right* to insist on receiving life-prolonging ANH, whereas the Court of Appeal concluded that Burke would merely be the *beneficiary of a duty* to provide such treatment, whose only right was to refuse it. Strasbourg did not engage with this issue;

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<sup>25</sup> HC esp [73].

<sup>26</sup> HC [166]. For analysis of the potential implications of Munby J’s derivation of a right to die with dignity, see John Coggon, ‘Could the Right to Die with Dignity Represent a New Right to Die in English Law?’ (2006) 14 *Medical Law Review* 219.

<sup>27</sup> HC [75], citing cases such as *Re C* [1994] 1 WLR 290, *St George’s Healthcare NHS Trust v S*, [1999] Fam 26 and *Re B* [2002] EWHC 429 (Fam).

<sup>28</sup> HC [130], [166] and [178].

<sup>29</sup> CA [31].

<sup>30</sup> CA [32], noting that the relevant case law was cited by Munby J at HC [82]-[87].

<sup>31</sup> CA [32].

its concern was with ensuring that the content of Burke's rights was protected, rather than with the precise domestic means by which that outcome is achieved. The Strasbourg court was therefore satisfied with the Court of Appeal's ruling that it would be murder 'to withdraw life-prolonging ANH from a patient who...[had capacity and] desired the treatment to continue'.<sup>32</sup>

There were two other significant differences between the approach of Munby J and the Court of Appeal.

*First*, the courts had a different response to a counterfactual situation in which during the final stages of Burke's life ANH would hasten his death, rather than prolong his life. Munby J's appeal to the patient's determinate right to autonomy indicates that, where it is the patient's wish, ANH should be provided in such circumstances.<sup>33</sup> In contrast, the Court of Appeal ruled that 'a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs'.<sup>34</sup> The Court of Appeal's response thereby leaves the decision to the judgment of the doctor. But why should a patient's prioritisation of relief from thirst over a marginally extended life be rejected in favour of a doctor's prioritisation of marginally extending his life? As Foster has pointed out, the 'odd' position of the Court of Appeal means that '[p]recisely when the patient is at his most vulnerable the law abandons him'.<sup>35</sup> It is not purely a clinical decision; it is a decision to be made solely by reference to the patient's interests and therefore properly made by the patient. The Court of Appeal's approach could not be supported by appeal to the policy of prohibiting euthanasia. In law, acting on a patient's request for life-shortening ANH is not equivalent to acting on a patient's request for a lethal injection. It is well established that a doctor may lawfully administer palliative care in circumstances where this has the incidental effect of shortening the patient's life.<sup>36</sup>

*Secondly*, the Court of Appeal's focus was entirely on ANH, whereas Munby J's principles had an apparently wider reach. As preliminary matters, his Lordship expressly declared that he was not addressing situations concerned with the prioritisation or allocation of scarce resources, or the provision of experimental or untested forms of treatment, because those issues did not arise in the context of ANH.<sup>37</sup> This has been taken by some to imply that his Lordship's reasoning extends beyond ANH – to all ordinarily available life-prolonging treatment or, according to the Court of Appeal, even beyond life-prolonging treatment.<sup>38</sup> With respect, the Court of Appeal was being most uncharitable; Munby J's judgment was clearly shaped by the nature of Burke's particular concerns and the GMC's guidance on the withdrawal/withholding of ANH and 'life-prolonging treatments generally',<sup>39</sup> and he makes repeated references to 'life-prolonging treatment'.<sup>40</sup>

Many academic commentators reject the suggestion of a *right* to insist on ordinarily available life-prolonging treatment or even ANH. Gillon considers such an approach to support the 'non-beneficial and wasteful provision of life prolonging

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<sup>32</sup> *Burke v UK* (No. 19807/06, 7 July 2006).

<sup>33</sup> HC [116].

<sup>34</sup> CA [55].

<sup>35</sup> C Foster, 'Burke: A Tale of Unhappy Endings' (2005) *JPIL* 293, 298.

<sup>36</sup> This was accepted by both the HC at [104] and the CA at [63]. For discussion of the relevant case law see Pattinson (n 10), 14-017.

<sup>37</sup> HC [27]-[28].

<sup>38</sup> CA [20]: 'it has been understood as bearing on the right to treatment generally, and not merely life-prolonging treatment'.

<sup>39</sup> HC [9].

<sup>40</sup> See eg HC [98] and [116].

treatment in general and artificial nutrition and hydration in particular'.<sup>41</sup> Mason and Laurie similarly bemoan his Lordship's support for rights-based approach over a communitarian/duty-based approach.<sup>42</sup> Neither work, however, defends the rejection of a rights-based autonomy focus beyond pointing to professional discretion and finite resources. What is properly regarded as 'non-beneficial and wasteful' and whether we should adhere to a rights-based over a duty-based perspective are issues requiring much deeper analysis. Elsewhere, I have defended the theoretical pre-eminence of a particular rights-based approach.<sup>43</sup>

Munby J's particular approach was to give great weight to the right to self-determination, relying on *Pretty v UK*<sup>44</sup> to support the view that Art 8 embraces 'such matters as how one chooses to pass the closing days and moments of one's life and how one manages one's death'.<sup>45</sup> That was despite the fact that this view on the ambit of Art 8(1) had been rejected by the House of Lords in *Pretty* before the case reached the ECtHR,<sup>46</sup> and the case law on s 2 of the Human Rights Act 1998 suggests that the lower domestic courts remain bound by decisions of the higher courts even when they are inconsistent with subsequent decisions of the ECtHR.<sup>47</sup> In any event, Munby J's statement on Art 8 does now represent the view of the UK's highest appeal court, which has subsequently departed from its own judgment in *Pretty* in favour of that of the ECtHR.<sup>48</sup>

In my view, Biggs is right to insist that concerns about the expansionist potential of a rights-based approach could have been dealt with in *Burke* by simply restricting the rights claim to *Burke*'s specific concerns.<sup>49</sup> The provision of ANH to someone in *Burke*'s position, for as long as he is not comatose, raises no real resource allocation difficulties additional to those raised by the Court of Appeal's position. Other life-prolonging treatment and other conditions may raise additional complexities but, as Biggs points out, future cases could consider and develop safeguards to ensure that the rights of others are fully protected in those contexts.

## **Withholding and withdrawing life-prolonging treatment from incapacitated patients**

The Court of Appeal considered Munby J's declarations to go far beyond the 'current concerns of Mr Burke'.<sup>50</sup> The Court of Appeal was particularly concerned with the fact that Munby J's declarations dealt with the position of incapacitated patients, when 'Mr Burke is likely to remain competent until the final stages of his illness' and

<sup>41</sup> Gillon (n 5) 810.

<sup>42</sup> JK Mason and GT Laurie, 'Personal Autonomy and the Right to Treatment: A Note on *R (on the application of Burke) v General Medical Council*' (2005) 9 *Edin LR* 123, esp 127 and 131. SD Pattinson, *Influencing Traits* (Ashgate 2002) ch 1 and Pattinson (n 10) ch 16.

<sup>43</sup> SD Pattinson, *Influencing Traits* (Ashgate 2002) ch 1 and Pattinson (n 10) ch 16.

<sup>44</sup> *Pretty v UK* (2346/02) (2002) 35 EHRR 1.

<sup>45</sup> HC [130], [166] and [178].

<sup>46</sup> *R (Pretty) v DPP* [2001] UKHL 61.

<sup>47</sup> See *Kay v Lambeth LBC* [2006] UKHL 10 as subsequently interpreted and applied in, eg, *R (Purdy) v DPP* [2008] EWHC 2565, [45]; [2009] EWCA Civ 92, [54]; [2009] UKHL 45, [32]. I have argued elsewhere that such an approach to domestic precedents is both wrong in principle and contrary to the actual reasoning of Lord Bingham in *Kay*, see SD Pattinson, 'The Human Rights Act and the Doctrine of Precedent' (2014) *Legal Studies* (DOI: 10.1111/lest.12049).

<sup>48</sup> *Purdy* [2009] UKHL 45, [36].

<sup>49</sup> H Biggs, "'Taking Account of the Views of the Patient", but only if the Clinician (and the Court) Agrees – *R (Burke) v General Medical Council*' (2007) 19 *CFLQ* 225.

<sup>50</sup> CA [22].

‘[w]e do not understand Mr Burke’s current concerns to relate to this stage and, if they do, we think that they are premature’. With respect, Munby J’s judgment makes it clear that:

The claimant wants to be fed and provided with appropriate hydration until he dies of natural causes. He does not want ANH to be withdrawn. He does not want to die of thirst. He does not want a decision to be taken by doctors that his life is no longer worth living.<sup>51</sup>

Burke’s expressed wishes refer to his life ‘until he dies’, which does mean that his concerns did relate to the final stage of his life. Indeed, as will be explained below, Burke should be understood to have been making an advance directive, which could not properly be dismissed as ‘premature’.<sup>52</sup>

Perhaps, Burke’s concerns were considered ‘premature’ because his medical prognosis was not entirely certain and his period in stage 2 might be only fleeting. Burke’s period in stage 2 could, however, be lengthier than expected and it is worth remembering that the case law is littered with examples in which medical predictions of a speedy decline have been proven wrong.<sup>53</sup> Since the court did hold as a matter of fact that Burke’s condition might enter three stages, it was legitimate for Munby J to examine the relevant law on Burke’s view on what should happen when he could no longer express a view.

Both Munby J and the Court of Appeal accepted that they were bound by authority to accept that the best interest test applies to incapacitated patients. The Court of Appeal, however, took issue with Munby J’s approach to the best interest test. By way of context, it should be noted that the Mental Capacity Act 2005 was passed in the period between Munby J’s judgment and the Court of Appeal’s decision, and came into force over two years later. The Court of Appeal was firmly of the view that the provisions of the 2005 Act were in accord with ‘the position at common law’.<sup>54</sup>

Munby J examined the case law in some depth, including that on patients in a permanent vegetative state (PVS) and incapacitated but sentient patients capable of being kept alive for an indefinite period by the provision of ANH. According to Munby J:

There is a very strong presumption in favour of taking all steps which will prolong life, and save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken. In case of doubt that doubt falls to be resolved in favour of the preservation of life. But the obligation is not absolute. Important as the sanctity of life is, it may have to take second place to human dignity. *In the context of life-prolonging treatment the touchstone of best interests is intolerability. So if life-prolonging treatment is providing some benefit it should be provided unless the patient's life, if thus prolonged, would from the patient's point of view be intolerable.*<sup>55</sup>

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<sup>51</sup> HC [6].

<sup>52</sup> For an earlier expression of this view see SD Pattinson, *Medical Law and Ethics* (1st edn, Sweet & Maxwell 2006), 484–486, esp n 44.

<sup>53</sup> Consider eg the pessimistic, but ultimately incorrect, predictions of life-expectance for the patients in *Re C* [1994] 1 WLR 290 and *R v Portsmouth Hospitals NHS Trust Ex p Glass* [1999] 2 FLR 905.

<sup>54</sup> CA [57].

<sup>55</sup> HC [116], as quoted in CA [61].



The Court of Appeal, when quoting the judge, added that emphasis to the last two sentences. It was declared that there could be no objection to the above summary ‘had it not contained the final two sentences, which we have emphasised’.<sup>56</sup> The Court of Appeal explained that it rejected the suggestion that ‘the touchstone of “best interests” is the “intolerability” of continued life’ and the situations of patients in PVS and the incapacitated but sentient kept alive by ANH were ‘very different’. With regard to a patient close to death – which the Court of Appeal strangely claimed did not relate to Burke’s ‘legitimate concern at this stage of his life’<sup>57</sup> – not only was ‘intolerably’ said not to be the test of best interests, but the Court of Appeal expressly rejected the idea that there was a ‘single test, applicable in all circumstances’.<sup>58</sup> So how are we to interpret and apply the best interests test in the final stages of life? The Court of Appeal refused to provide any guidance beyond asserting that ‘it is best to confine the use of the phrase “best interests” to an objective test’.<sup>59</sup> This approach seemed to be articulated solely as a way of denying the need to attach particular weight to Burke’s subjective understanding of the benefit of continued ANH. Burke’s explicit desire to avoid dying of thirst and hunger indicates that he considers avoidance of that experience at the end of his life to be a benefit. From his point of view, the continued provision of ANH would be neither futile nor intolerable, but in his best interests.

The Court of Appeal’s approach to the best interest test was rather too quick given that it did not examine any of the case law in depth and seems to assume that the application of an objective best interest test is self-explanatory without elaboration. When referring to the 2005 Act, the Court of Appeal asserted that ‘section 4 does no more than require this to be taken into consideration when considering what is in the best interests of a patient’.<sup>60</sup> Subsequent case law has shown a willingness to grant greater weight to the previously autonomous wishes of an incapacitated patient than the Court of Appeal was willing to countenance.

In *Aintree University Hospitals NHS Foundation Trust v James*, the Supreme Court considered the application of the 2005 Act to a patient in a minimally conscious state.<sup>61</sup> David James had suffered multi-organ failure with severe brain damage and was dependent on artificial ventilation. The hospital trust sought declarations that it would be in James’ best interests to withhold specified types of invasive treatment if his condition deteriorated. Lady Hale, with whom the other Supreme Court justices agreed, reaffirmed that the starting point is a strong presumption that it is in a person’s best interests to stay alive, but that is not an absolute and ‘there are cases where it will not be in a patient’s best interests to receive life-sustaining treatment’.<sup>62</sup> Lady Hale noted that ‘there has been some support for a “touchstone of intolerability” in those cases [not concerned with patients in PVS] where a balancing exercise is to be carried out’.<sup>63</sup> Her Ladyship was, however, faced with a conflict over the meaning of a related touchstone – ‘futility’ – by the first instance judge and the Court of Appeal. The judge had asked whether the proposed treatment would be futile in the sense of ineffective or of no benefit to the patient. The Court of Appeal rejected that

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<sup>56</sup> CA [61].

<sup>57</sup> CA [56].

<sup>58</sup> CA [63].

<sup>59</sup> CA [29].

<sup>60</sup> CA [57].

<sup>61</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

<sup>62</sup> *Ibid.*, [35].

<sup>63</sup> *Ibid.*, [37].

approach to the best interests test, ruling that the treatment would be futile if it would have no real prospect of curing or at least palliating the patient's condition. The Supreme Court sided with the first instance judge.<sup>64</sup> Treatment could be a benefit to a patient 'even when it did not cure or palliate, where the burdens were outweighed by the benefits of continued existence'.<sup>65</sup>

Significantly, the Court of Appeal rejected the suggestion in the Court of Appeal that the best interests test required an objective assessment of the patient's wishes and feelings. Lady Hale declared that:

The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are...insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.<sup>66</sup>

There is much in *Aintree* that is inconsistent with the approach of the Court of Appeal in *Burke*. For a start, the refusal to accept that Burke had concerns about stage 2 was tantamount to replacing his actual wishes and feelings with the Court's own assessment of his wishes and feelings, which Lady Hale tells us we must not do. Indeed, the Court of Appeal had expressly rejected assessment of the best interest test from the patient's point of view in favour of an objective test, which is the converse of the position articulated by the Supreme Court. The Court of Appeal in *Burke* denied that intolerability and futility were notions capable of providing any guidance when assessing whether treatment was of some benefit to a patient in the final stages of his life, whereas Lady Hale found utility in both notions. Lady Hale was not, of course, seeking to defend a right to treatment of the form advanced by Munby J, but she gave a very different emphasis to the weight to be attached to the patient's previous views on what is or is not a benefit to the patient. The approach of the Supreme Court makes it much harder for the concerns of Burke to be dismissed when he enters a minimally conscious state at stage 2. It seems to me that it supports a far stronger presumption that ANH should be continued until he dies than follows from the approach of the Court of Appeal.

### **Advance directives**

Another reason given by the Court of Appeal as to why Munby J's declarations went far beyond the current concerns of Burke was that 'they address the effect of an advance directive, sometimes referred to as "a living will", when Mr Burke has made no such directive'.<sup>67</sup> As indicated above, Burke was just as concerned with his future as a locked in but aware patient as he was with the position in which he was in at the time of the litigation. Thus, he ought to have been taken to be making an advance request to the effect that ANH should continue until his death. The Court of Appeal were, perhaps, misled by Munby J's statement that certain issues '[m]ay turn upon the

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<sup>64</sup> Ibid, esp [40].

<sup>65</sup> Ibid, [40].

<sup>66</sup> Ibid, [45].

<sup>67</sup> HC [22].

precise terms of the claimant's advance directive'.<sup>68</sup> But Munby J was not thereby stating that Burke had not made an advance directive, but recognising that the precise form of that directive could well have changed by the time (some years hence) that Burke loses capacity.

The right to dignity and the right to autonomy were said by Munby J to underpin the legal right to make a binding advance refusal, which he extended to encompass a legal right to making a binding advance request for ANH. According to his Lordship, an incapacitated patient's right to dignity under Art 3 meant that if he has made

an advance directive which is both valid and relevant to the treatment in question... [then] his *decision to require the provision* of ANH which he believes is necessary to protect him from what he sees as acute mental and physical suffering is...in principle determinative.<sup>69</sup>

This was another step too far for the Court of Appeal. It held that the common law position on advance requests was identical to that under the Mental Capacity Act 2005.<sup>70</sup> The 2005 Act was said to regard advance requests as an important consideration when assessing what is in the best interests of a patient (under s 4(6)(a)), but not to give advance requests the binding force granted to advance refusals under s 26. The Court of Appeal did not analyse s 26 in any depth. The section itself does not actually state that an applicable advance refusal is binding, rather s 26(1) states that a valid and applicable advance decision 'has the effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued'. In other words, all s 26 does is say that a valid and applicable advance refusal has the same effect as a valid contemporaneous refusal and it is the common law that says that a valid contemporaneous refusal is binding.<sup>71</sup>

Subsequent case law has confirmed that where the 2005 Act offers equivalent protection to the common law, its provisions replace the common law;<sup>72</sup> but the common law may nonetheless extend protection to persons beyond that offered by the Act.<sup>73</sup> Further, under s 3 of the Human Rights Act 1998, the provisions of the 2005 Act must be read to give effect, as far as possible, to the Convention rights. Thus, it remains possible for the courts to recognise advance requests for ANH to be given to patients in the final stage of their lives as having binding force. The case law as it stands does not support such a position, but we have already seen that the best interest test is now recognised as giving much greater weight to a patient's previous wishes than had been accepted by the Court of Appeal in *Burke*.

Consider *X Primary Care Trust v XB*.<sup>74</sup> Theis J was concerned not with an advance request for treatment as in *Burke*, but with an advance refusal; nonetheless, his Lordship's approach to the previous wishes of the now incapacitated patient is

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<sup>68</sup> HC [175].

<sup>69</sup> HC [169].

<sup>70</sup> CA [57].

<sup>71</sup> See eg *Re T* [1993] Fam 95 and *Re B* [2002] EWHC 429.

<sup>72</sup> Eg *ZH v Metropolitan Police Commissioner* [2012] EWHC 604, [44].

<sup>73</sup> Eg *Re L* [2012] EWCA Civ 253, where the Court of Appeal confirmed that the court could intervene to protect an adult who *just* satisfies the 2005 Act's capacity test (and therefore falls outside of the Act), but is unable to exercise an autonomous choice because of factors such as coercion and undue influence.

<sup>74</sup> *X Primary Care Trust v XB* [2012] EWHC 1390.

instructive. First, Theis J relied on oral evidence as to the patient's wishes to interpret references to 'non-invasive ventilation' in his written advance refusal to refer to an invasive ventilation device, which involved a tube being passed into his windpipe. Secondly, his Lordship declined to treat the words 'valid until' followed by a now expired date as indicating that the advance refusal was time-limited on the basis that such an interpretation did not represent the patient's view. Theis J thereby sought to give maximal recognition to the patient's actual will when interpreting his advance directive. This stands in complete contrast to the Court of Appeal in *Burke*, which was not even willing to interpret Burke's statements as an advance directive.

### The need to involve the Court

Munby J declared that there were a number of situations where it would be unlawful to withdraw ANH from an incapacitated patient without judicial sanction.<sup>75</sup> One such situation was where a doctor wishes to withdraw or withhold ANH where the evidence suggests that the patient when capacitated would have wanted it to continue in the relevant circumstances.<sup>76</sup> His Lordship was of the view that the ECtHR's decision on Art 8 in *Glass v UK*<sup>77</sup> had transformed what was previously only a requirement of good practice into a legal requirement.<sup>78</sup> According to the Court of Appeal, however, Munby J was simply wrong to postulate such a legal duty. *Glass v UK* was said to have considered the implications of the doctors' conduct in the light of Strasbourg's understanding of English law and the specific situation in *Glass* had concerned a child.<sup>79</sup> When it comes to incapacitated adults, the court was said to have the power to declare the legal position but not to change it.<sup>80</sup> A declaration merely specifies what may take place with or without a declaration. There were situations where it was 'advisable' for a doctor to seek court approval. The House of Lords in *Bland* had given withdrawal of ANH from a patient in PVS as an example of where court approval should be obtained '*as a matter of good practice*'.<sup>81</sup>

The Court of Appeal thereby expressly rejected the idea that it had law-making functions,<sup>82</sup> at least in this context:

So far as the criminal law is concerned, the court has no power to authorise that which would otherwise be unlawful....Nor can the court render unlawful that which would otherwise be lawful. The same is true in relation to a possible infringement of civil law.<sup>83</sup>

The ECtHR saw no reason to doubt that this view was in accordance with Burke's Convention rights. The Strasbourg court was satisfied that a doctor was 'fully subject to the sanctions of criminal and civil law' and was therefore only recommended to obtain legal advice 'where a step is controversial in some way'. The Court declared:

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<sup>75</sup> HC [202].

<sup>76</sup> HC [214].

<sup>77</sup> *Glass v UK* [2004] 1 FLR 1019.

<sup>78</sup> HC [210].

<sup>79</sup> CA [75]–[80].

<sup>80</sup> CA [71].

<sup>81</sup> CA [71].

<sup>82</sup> Compare the interpretative theory of law, see eg R Dworkin, *Law's Empire* (Hart Publishing 1986), and the declaratory theory of law, see eg A Beever, 'The Declaratory Theory of Law' (2013) 33 OJLS 421.

<sup>83</sup> CA [71].

Any more stringent legal duty would be prescriptively burdensome – doctors, and emergency ward staff in particular, would be constantly in court – and would not necessarily entail any greater protection.

The ECtHR thereby accepted the debate as framed by the Court of Appeal, which focussed on whether the need to involve the court was a matter of good practice or a legal requirement.

The Court of Appeal placed some emphasis on the Intensive Care Society's estimation that the application of Munby J's criteria would lead to around 10 applications a day being made to the courts.<sup>84</sup> Resource issues thereby seemed to have influenced Court of Appeal's view that Burke was not entitled to impartial adjudication if stage 2 were to give rise to a conflict between his and clinical opinion on the continued provision of ANH. Not only did Burke not have a right to ANH, he did not even have a right to judicial consideration of his case. The Court of Appeal's approach unfortunately meant that it did not consider it necessary to opine on when a step would be sufficiently controversial to render it good practice to seek a declaration. It was, however, apparent that its list would have been much shorter than Munby J's, because it suggested that Burke would not have brought his case before the court had he been 'well advised'.<sup>85</sup> The Court of Appeal should, at the very least, have recognised that patients in, what we would now call, a minimally conscious state are more vulnerable when it comes to the withdrawal of ANH than patients in PVS.

## Conclusion

The general direction of medical law over the last few decades has been away from medical paternalism towards patient autonomy.<sup>86</sup> *Burke* represents a notable exception, save for Munby J's 'path-breaking' judgment'.<sup>87</sup> The issue is not that patients must always have what they want, which Lady Hale was right to reject as an unrealistic goal. The Court of Appeal, however, left patients like Burke to live in fear that when they reach the point of being aware but unable to complain about their thirst and hunger – a point at which they could hardly be more vulnerable – their desire for continued ANH could be sacrificed on the basis of clinical opinion without the need for impartial adjudication. The recent Supreme Court decision in *Aintree* at least offers reassurance that the best interest test is to be interpreted from the viewpoint of such patients, giving their previously expressed wishes particular weight.

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<sup>84</sup> CA [69].

<sup>85</sup> CA [13].

<sup>86</sup> See Pattinson (n 10), chs 4 and 5.

<sup>87</sup> P Fennell, 'The Right to Require Life-Prolonging Treatment' [2004] 3 *Med LR* 306, 315.